

# Testing innovative strategies to reduce the social gradient in the uptake of bowel cancer screening: a programme of four qualitatively enhanced randomised controlled trials

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## Scientific summary

### Reducing the social gradient in uptake of bowel cancer screening

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# Scientific summary

## Background

Bowel cancer is the third most common cancer in the UK and the second most common cause of cancer death. This significant public health burden can be diminished by screening using the guaiac faecal occult blood test (gFOBT), which reduces bowel cancer mortality by 16% among people offered screening. The NHS Bowel Cancer Screening Programme (BCSP) commenced biennial screening in 2006 and now offers gFOBT to 60- to 74-year-olds in England.

Overall, screening uptake [defined as the return of a gFOBT kit within 18 weeks of the invitation that led to a 'definitive' test result of either 'normal' (i.e. no further investigation required) or 'abnormal' (i.e. requiring referral for further testing, usually colonoscopy)] is about 56%, but uptake varies from 61% in the least deprived to 35% in the most deprived areas of the country. Uptake within South Asian communities further varies: 31.9% in the Muslim community, 34.6% in the Sikh community and 43.7% in the Hindu community when compared with 'non-Asians'. Previous research to tackle socioeconomic inequalities in uptake has focused on specific underserved groups rather than reducing the gradient in uptake across the entire population.

Therefore, we explored reasons for non-uptake and subsequent uptake of bowel cancer screening in men and women from different socioeconomic backgrounds in England (London and Yorkshire) and in South Asian communities in London (workstream 1). We developed and tested four theoretically derived, novel interventions that aimed to increase uptake among individuals with lower socioeconomic circumstances (SECs) without compromising uptake in any socioeconomic group (workstream 2). We then tested the effectiveness and cost-effectiveness of our interventions in four randomised controlled trials (RCTs), which incorporated the interventions within the NHS BCSP (workstream 3).

## Objectives

Overall objective: to reduce socioeconomic inequalities in bowel cancer screening uptake without compromising uptake in any socioeconomic group.

### *Objectives of each workstream*

Workstream 1: to explore psychosocial and cultural determinants of low uptake of gFOBT in the general population and in South Asian communities.

Workstream 2: to develop and test four theoretically based interventions designed specifically to reduce the socioeconomic gradient in bowel cancer screening uptake.

Workstream 3: to use a RCT design to evaluate the effectiveness and cost-effectiveness of each individual intervention within the NHS BCSP.

## Workstream 1

### *Methods*

We conducted 18 focus groups with individuals eligible for screening and from a range of socioeconomic backgrounds in London and South Yorkshire. Sixteen groups were recruited via a postal invitation sent from the NHS BCSP. One group was recruited via a community setting and another via a market research recruitment agency.

In addition, we carried out interviews with individuals who acted as key informants for a variety of South Asian communities in London. South Asian communities were chosen because they represent the largest ethnic minority group in England (approximately 7% of the population) and low uptake of colorectal cancer (CRC) screening in the UK has continued to be identified within all South Asian religolinguistic groups even when age, deprivation and gender are adjusted for. Key informants were purposively sampled to ensure representation from the three dominant faith backgrounds (Islam, Hinduism and Sikhism). Interviews were recorded, transcribed and analysed using thematic analysis.

## Results

### Focus groups

In all, 128 men and women from diverse occupational backgrounds took part in a focus group. The majority of participants recalled receiving invitation(s) and gFOBt kit(s) from the NHS BCSP. One hundred participants reported gFOBt non-uptake on at least one occasion, of whom 31 went on to complete the gFOBt kit when invited to take part in a subsequent screening round. Nine participants had not completed the gFOBt kit owing to having had investigations outside the NHS BCSP, such as colonoscopy, endoscopy or gFOBt kit completion in primary or private care.

We identified the following themes summarising why people did not to take part in the NHS BCSP: (1) risks to hygiene and personal risk posed by dealing with faeces; (2) detachment from familiar health-care settings; (3) implications of knowing the screening results; (4) judgements of good health and low levels of screening; and (5) delaying uptake leading to non-uptake.

Among individuals who had not taken part in screening in one episode but had subsequently participated, the key 'tipping point' that changed their decision was discussions about bowel cancer and screening with their peers.

### Key informant interviews

Interviews were conducted with 16 London-based 'key informants' representing three South Asian faith communities in order to explore reasons for the variability of low uptake between faith communities and to identify reasons for low uptake of bowel cancer screening in South Asian communities as well as strategies by which uptake might be improved. Twelve key informants held roles in faith, community or charity organisations and four were general practitioners (GPs). Across South Asian faith groups key informants identified limitations posed by the written word, low awareness of CRC and screening, difficulties with handling faeces and gFOBt completion as reasons for low bowel cancer screening uptake. In addition, written materials were deemed particularly inappropriate for the Sylheti-speaking Bangladeshi Muslim community and a social stigma surrounding cancer was described in Sikh communities, which may hinder engagement with screening. Non-written information delivered within faith or community settings was preferred across all faith groups.

Efforts to increase accessibility to bowel cancer screening in South Asian communities should use local ethnic media and face-to-face approaches within community and faith settings to increase awareness of bowel cancer and screening, to address challenges posed by written materials and to challenge the social stigma surrounding cancer.

## Workstream 2

We developed and tested four theoretically grounded, simple, low-cost interventions that could easily be implemented within the NHS BCSP.

**Intervention 1: a 'gist' leaflet**

We undertook qualitative research to establish how the existing NHS BCSP materials were received. We then designed a leaflet summarising the key screening information in language suited to respondents with low health literacy and tested the leaflet for readability and comprehensibility via a number of small qualitative studies. Next, we conducted a multicentre RCT with individuals approaching the screening-eligible age ( $n = 4452$ ) to examine the impact of the leaflet on intentions to complete screening. We found that inclusion of the gist-based leaflet alongside the standard screening information materials increased knowledge of bowel cancer and bowel cancer screening, but did not increase intention to participate in screening. However, we found that the RCT respondents in both the intervention and control groups had very high intention levels.

**Intervention 2: a 'narrative' leaflet**

We conducted 20 narrative style interviews with individuals who had some experience of taking part in bowel cancer screening. A narrative leaflet based on the 'stories' told was developed. The leaflet was particularly consistent with workstream 1 findings concerning resistance to handling faecal matter, the implications of knowing gFOBt results and the power of talk.

We designed the leaflet in consultation with a leading social marketing group and refined the leaflet design before user testing it via a number of focus groups and interviews, which resulted in further minor refinements. We then conducted a multicentre RCT with screening-naïve individuals ( $n = 4125$ ) to examine the impact of the leaflet on screening intentions. The addition of the narrative leaflet to standard information material had a positive effect on intention to take part in the NHS BCSP and on beliefs about bowel cancer screening, which were previously found to be predictive of intention.

**Intervention 3: general practice endorsement**

Following insights from the workstream 1 focus groups about the perceived lack of involvement of known and trusted NHS information sources, and in consultation with our Primary Care Advisory Group (five GPs, a practice manager, a NHS BCSP hub director and two clinical academics), we developed text that would appear on the NHS BCSP invitation materials and designed materials to invite GPs to agree to have their practice endorse the NHS BCSP. We then invited all GPs across England to endorse the NHS BCSP. In total, after sending up to three reminder letters, 80% of GPs agreed to endorse the programme.

**Intervention 4: enhanced reminder**

First, we asked NHS BCSP staff to note details of telephone calls to the NHS BCSP helpline directly relating to the usual reminder letter to assess what issues were raised by potential participants at this stage. We then developed an enhanced reminder (ER) letter to address specific concerns that inhibit test completion, particularly among subjects with lower SECs, including lack of awareness of bowel cancer and of perceived benefits of bowel cancer screening. We then user tested the ER letter in four focus groups ( $n = 26$ ).

**Workstream 3****Methods**

National, cluster-randomised trials compared 'usual care' with each of four intervention strategies designed to target known barriers to uptake among people with lower SECs. Each strategy supplemented existing NHS BCSP information/invitation materials with (1) 'gist' information ( $n = 163,525$ ), a leaflet summarising key information in language suited to respondents with low health literacy; (2) 'narrative' information ( $n = 150,417$ ), a leaflet describing the experiences of people who had participated in screening; (3) a general practice endorsement (GPE) added to the screening invitation letter ( $n = 265,434$ ); and (4) enhancing the reminder letter by reiterating the screening offer (ER,  $n = 168,480$ ) sent to initial non-responders. SECs were measured using the Index of Multiple Deprivation (IMD) score associated with each individual's home address. Change in the socioeconomic gradient in uptake (interaction between treatment group and IMD quintile) was the primary outcome.

Randomisation was based on day of invitation. Trials 1 and 2 (gist and narrative) were run over 10 consecutive days between 5 and 16 November 2012 and 4 and 15 March 2013, respectively. Trials 3 and 4 (GPE and ER) were run over 20 consecutive days between 3 and 28 June 2013 and 8 July and 2 August 2013, respectively. Two weeks before the start of each intervention a randomisation number sequence was generated. For trials 1 and 2, randomisation schedules were sent to REAL Digital International (Croydon, UK) for the Southern, London and Eastern Hubs, and the 'in house' invitation system for the North East and Midlands and North West Hubs. For trials 3 and 4, randomisation was undertaken directly through the Bowel Cancer Screening System. Schedules were not provided to the hubs and were instead sent to the Health and Social Care Information Centre (HSCIC), formerly Connecting for Health. Hubs were 'blind' to the randomisation schedule and confirmed whether or not the intervention was included on the S1 letter every day, which the trial office then checked against the randomisation schedule. For each set of numbers, days were randomly allocated to the intervention materials plus standard materials or standard materials alone.

Although subsequent blinding was not possible, there was no direct contact with subjects (avoiding biasing participation) and subjects were unaware of the comparator intervention, unless a member of their household received an invitation during the study period that contained different information materials or if they had been invited on a previous occasion and recalled the exact content of the previous invitation.

### Findings

Baseline characteristics were well balanced for each trial and representative of the population served by the NHS BCSP. Overall uptake (across the two arms) was 57.4%, 57.7% and 57.9% for trials 1, 2 and 3, respectively, and 25.4% in the ER trial (trial 4), which only targeted individuals who had not responded to the first invitation. In all four trial populations, uptake was strongly negatively associated with deprivation, with the difference between the least and most deprived quintiles in each control arm ranging between 20% and 24%.

The effects of the interventions within IMD quintiles are expressed as adjusted odds ratios (ORs). For the gist trial, the difference in uptake between the intervention and control arms was +0.2% in the least deprived group and +1.0% in the most deprived group. The effect did not differ by IMD quintile (least to most deprived quintiles: unadjusted ORs 1.01, 0.99, 1.01, 1.00, 1.04, interaction  $p = 0.6$ ; adjusted ORs 1.06, 1.02, 1.00, 1.01, 1.04, interaction  $p = 0.7$ ). There was no significant increase in overall uptake [unadjusted OR 1.02, 95% confidence interval (CI) 0.92 to 1.13;  $p = 0.8$ ; adjusted OR 1.03, 95% CI 0.99 to 1.06;  $p = 0.1$ ]. The median number of days to return the test kit was 23 in the intervention and 22 in the control arm.

Similarly, for the narrative trial, there was no significant differential effect of the intervention on uptake between the least and most deprived groups (-2.2% and -3.6%, respectively). The effect did not differ by IMD quintile (least to most deprived quintiles: unadjusted ORs 0.91, 0.97, 0.95, 0.91, 0.86, interaction  $p = 0.4$ ; adjusted ORs 0.98, 1.00, 1.05, 1.00, 0.92, interaction  $p = 0.1$ ). There was also no effect on overall uptake (unadjusted OR 0.93, 95% CI 0.81 to 1.06;  $p = 0.3$ ; adjusted OR 1.00, 95% CI 0.96 to 1.03;  $p = 0.8$ ). The median number of days to return the test kit was 26 in both arms.

In the GPE trial, there was a slight differential change: -0.8% and +1.4% in the least and most deprived groups. There was also a trend towards a modest SEC gradient in effect; however, this heterogeneity was not significant (unadjusted ORs 0.97, 1.02, 1.06, 1.06, 1.06;  $p = 0.3$ ; adjusted ORs 1.04, 1.06, 1.08, 1.09 and 1.07 for the least to most deprived quintiles respectively;  $p = 0.5$ ). Although the unadjusted OR indicated little effect for overall uptake (unadjusted OR 1.03, 95% CI 0.95 to 1.11;  $p = 0.5$ ), the effect became significant after adjustment for other factors (adjusted OR 1.07, 95% CI 1.04 to 1.10;  $p = 0.0001$ ), mainly owing to differences in effect sizes between arms by screening episode (first time, prevalent, incident). The median number of days to return the test kit was 23 for the intervention and 22 for the control arm.

In the ER trial, the difference in uptake between the intervention and standard arm was  $-0.2\%$  and  $+0.8\%$  in the least and most deprived groups, respectively. There was a significant interaction with IMD quintile (least to most deprived quintiles after adjustment for other factors: unadjusted ORs 0.99, 1.05, 1.10, 1.05, 1.07;  $p = 0.3$ ; adjusted ORs 1.00, 1.04, 1.13, 1.09, 1.11;  $p = 0.005$ ) with a greater effect in the most deprived quintile (adjusted OR 1.11, 95% CI 1.04 to 1.20;  $p = 0.003$ ) than the least deprived (adjusted OR = 1.00, 95% CI 0.94 to 1.06;  $p = 0.98$ ). The unadjusted OR did not indicate a statistically significant difference in overall uptake between intervention and control arms (unadjusted OR 1.04, 95% CI 0.95 to 1.14;  $p = 0.4$ ), but the effect became significant after adjustment (adjusted OR 1.07, 95% CI 1.03 to 1.11;  $p = 0.001$ ). The median number of days to return the test kit was 11 in both arms.

The average marginal costs per person screened of providing the gist and narrative leaflets were £0.04 and £0.05, respectively. The GPE and ER trials incurred a one-off cost to modify the standard invitation and reminder letters within the NHS BCSP information technology system of £78,000, but this cost would not be incurred again if the interventions were implemented. The average marginal cost per person screened with these interventions was therefore zero.

## Conclusion

Three out of four trials of interventions aimed at tackling inequalities in screening uptake failed to reduce the SEC gradient. An ER letter was the only strategy to significantly reduce the gradient, while GPE increased overall uptake. Given their minimal cost, these interventions could be implemented immediately to support the enhanced and equitable delivery of cancer screening within the NHS BCSP. The results of these trials are testament to the difficulty of modifying inequalities in screening within an organised programme, but they highlight the importance of continuing to research effective strategies to achieve equity in early diagnosis of cancer.

## Trial registration

This trial is registered as ISRCTN74121020.

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